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Real Life

NOLA MILLIN &
SHIRLEY McNAUGHTON



Nola Millin

Having just read through all of the articles that are in this issue, all I can say is "Wow"! We have a lot of stuff that will hopefully make the reader think. The theme of this issue is "The Real World." I'm sure as readers you are wondering what we mean by "The Real World." After all, isn't the world we live in real? The answer to that question can be more complex than expected so we devoted an entire issue to it. If memory serves me correctly, when this topic was brought up at this year's annual editors' meeting I was quite vocal about my opinions on it (people who know me won't be surprised!), so that's why I'm doing this editorial.

One of the reasons I have such strong opinions on coping in the real world is because I see so many people who don't know how to cope in their worlds. I'll be polite in

saying that it bothers me, when to be honest I should say that it frustrates me no end. In case you are a new reader to **Communicating Together**, I should tell you that I'm an AAC user. I can communicate verbally to people who are close to me but I use a word board and voice output device when I need to. I communicate quite effectively using these three means plus written communication. Friends often say, "For someone who's speech impaired, you sure do talk a lot!" Shirley McNaughton has said that Paul Marshall and I tend to identify more with the "speaking" population than with other AAC users. I say this just to give the reader some indication of where I'm coming from as I give my opinion on this topic of "The Real World."

So, why do I get frustrated when others can't cope in their worlds? Well, I strongly feel it's from a lack of preparation for "real life." Bear with me and I will attempt to explain. I live in an apartment building that has attendant care available 24 hours a day seven days a week. Although there is attendant care, this is still an apartment building where we are free to come and go or to have visitors anytime we want. Meals are prepared in our apartments by staff at times we want to have them. It's independent living and we are as independent as we want to be. I have lived in this building for almost 18 years so I've seen a lot of things. One of the biggest things is the fact that some people haven't been prepared for "real life" so they don't know how to cope with things they encounter when living in an independent living facility.

Some people move in here directly from their parents' home. They have usually had some sort of "life skills" course which teaches the basics in money management, doing laundry, cooking, and a few other needed tasks. Other people move in after a two-year apartment-training program, which teaches all the needed skills for independent living. I see a problem surface when some of these people are faced with relating to the thirty various staff members who work with us. Appropriate social skills seem to be lacking.

I realize that we all react to situations and to people differently but I often wonder what makes the difference in these two groups so large. There are the two extremes. There are the tenants who don't seem to have any contact outside the building and get attached to each staff member who comes through the door. There is large staff turnover so when a staff member leaves, the whole world of this type of tenant caves in. I'm not saying tenants and staff shouldn't become friends but tenants shouldn't become *dependent* on that one staff member to do a lot of things for them since circumstances change and staff move on. The other extreme are those individuals who haven't seemed to learn to deal with different personalities. They don't think twice about saying, "You're stupid" to a staff member they might not like and they refuse to get assistance from that person. Both of these extremes are dangerous because the person with a disability is ultimately the one who will be hurt. What if the person needs to go to the washroom but the only avail-

able staff member is the one they have refused care from?

Observing the two extremes has caused me to wonder if children who are disabled are getting the right training from their life experiences. I'm certain that children and adolescents who are disabled come in contact with many more professionals in their daily life than their able-bodied peers, e.g., physio-therapist, occupational therapist, speech-language pathologist, psychologist, seating specialist, social worker, three or four in-home workers, as well as teachers and teacher aides. Although, it's a fair number of individuals, each one usually knows the child. They learn the child's needs and how the child communicates. If they change, usually the parent deals with and eases the transition. As children with disabilities grow into adolescence they have limited experiences in dealing with changing staff on a regular basis.

New staff can be challenging to anyone. New staff receive "basic training" but they don't know our routines and the ways in which each person likes things done. For a person with a disability, who isn't accustomed to change, it can be a very difficult situation for both the new staff member and for the individual. The additional challenge comes when the person with a disability is an AAC user and communication doesn't flow easily.

Although I have used my living facility as the example, I see this same problem in other situations. Many people with disabilities lack, what I refer to as "common sense." They don't seem to know how to relate to the world around them. Is it that they've been overprotected by their parents and by the environment in which they grew up where every-

thing was adjusted to meet their needs? Or is it that they haven't been given appropriate training for their real world? These questions haunt me.

I'm one of the people who is called upon to do some of the training now. I have developed a business where I do motivational speaking and sensitivity training. I tell nondisabled people how to be more sensitive to people who have disabilities as they enter the mainstream world. Yet, after reading these articles, I'm wondering if I should be spending more time with individuals who have disabilities, helping them to cope with *their* real world — a world which is far from perfect.

* * * * *

The articles in this issue have given me much fuel for thought. The feature is by Barbara Collier. She describes her course for AAC users in safeguarding themselves against all kinds of abuse. When I read her article, I thought about my early life. I was enrolled in a sheltered school environment until I was slowly integrated into a regular school at age seventeen. It wasn't until I entered high school that I got any education about sex or about what to do if I were assaulted. Fortunately, I had a very liberal mother who taught me sex education. I would certainly have been able to tell her if I had been abused.

Thinking about it though, now that I'm an advocate for disabled individuals, I'm not sure if I would be smart enough to recognize if an AAC user was trying to tell me that she or he was being abused especially if the person had a limited vocabulary. The AAC device is rarely set up to convey a message such as that and listeners aren't always on the same thought wave. If someone indicated,

"The person is bad," I'm not sure if I would clue in to what the AAC user might be telling me. I know how much a course like Barb Collier's is needed. Many consumers don't know basic human rights and are too afraid to say anything if they have been violated. I have just gone through a workshop to become an advocate for other individuals who have disabilities because there is abuse and neglect happening but people are afraid to report it. Some people aren't even aware that abuse shouldn't be a part of their world.

At the other end of the spectrum come the articles from Audrey McGee and Steven Hanlon. They have both lived in two worlds and have had many experiences. They share what their *real world* is like now that they live in a hospital. It is very interesting to see how they have adjusted and are now content in their environment. It is a "world" that many of us might find difficult to adjust to. Though, as Audrey states, she has many things to do and is always learning new things.

In her own article, Alda Steprans shares how inadequate she felt when she started nursing at the hospital where Audrey and Steven live. I understand Alda's feelings. I recently took on a volunteer job at a nursing home — a very foreign place to me. As I get to know the residents, I am learning about their world. I am learning to accept their world instead of comparing it to mine. They are happy in their world, just like Audrey and Steven are happy in theirs. Although I can't imagine myself being happy in a place such as a nursing home, that doesn't matter. What matters is my acceptance of *their* world.

Shirley McNaughton talks about this very thing in *SymbolTalk*. As I read Shirley's article, I suddenly

realized that I'm guilty of thinking my "real world" is the "world" everybody should live in. Shirley emphasizes what I've just said — we need to accept where people are at. I need to realize that not everyone can cope in the world I live in. Just because I don't perceive something as a major issue doesn't mean that the tenant down the hall is crazy for getting up in arms about it. Shirley stresses the need to prepare children for their "world." She says that options should be left open and she emphasizes the importance of the role of "helpers". I agree fully. I know that I wouldn't have gotten as far as I have without a lot of "helpers." I'm writing this editorial the day after going to my high school reunion. It's a long story but my high school was very inaccessible so a bunch of guys were assigned to carry me up and down the flights of stairs. Many years later, one of those guys is a close friend of mine. I went to the reunion with him and his wife. I met lots of people and my world opened up by attending that inaccessible school.

As usual, Paul Marshall has written an excellent article in *Paul's Place*. Once again the underlying message of Paul's article is to learn to accept each other's worlds. I can identify with Paul all too well. I'm known for my independence. Like Paul, I'm learning that sometimes asking for help is necessary to survive. Sometimes it's just easier for everyone else around me if I ask for help since I take longer to do something. I love the quote Paul used from Shirley McNaughton about how independence is knowing when to ask for help. Read Paul's article for the actual quote. Thanks Paul for sharing your insights!

Geb Verburg has provided a delightful article in *Contexts*. He

shares the story of Chris Aubé's childhood. It's charming for it shows Chris's independence even to his mother's horror. We then hear from Chris himself. He is now a college student. Chris shares how Blissymbols opened up the world to him at a young age.

We have two articles in the *Perspective*. Peter Moore tells how each person has potential but may need help to reach that potential. I feel when a person is reaching their potential, they will be able to cope in their "worlds." The experiences we encounter as we reach our potential help us be the best we can be in our own "real worlds." George Pigache's *Perspective* shows us how communication aids help or don't help, students experience real life or reach their potential. He feels a lot of time is spent on facilitating the communication of *needs* when students should be able to communicate about all types of experiences and all that life offers. I recently spoke with a speech-language pathologist who voiced the same frustration. She asked, "How is it that you actually communicate *everything* you want with your device(s)? You're able to socialize and converse about a wide range of topics." I'm not sure what makes people like me, or the student George talks about, different. In my case, people saw my potential and kept pushing me to reach it. I learned how to express myself along the way!

Hopefully, as you read this issue, you will realize, as I did, that each one of us lives in our own "real world." We have a responsibility to prepare children and adults for the world they're facing but we don't have the right to make them fit into our worlds. I hope everyone is as content in their "real world" as I am in mine!

A Postscript from Shirley McNaughton

To quote from Nola, several articles in this issue provide "fuel for thought"! Nola's editorial is a wonderful example of *her* ongoing ability to learn. Life-time receptiveness to new ideas is to be treasured! As a teacher, I have always realized how precious new ways of thinking can be. In recent years, I have seen new vistas regarding the rights of persons with disabilities. As George Pigache identifies, however, our great challenge is closing the gap between what is now conceptualized, or even possible technically, and what is actually happening.

Again, I am inspired by the sensitivity of Alda Steprans' writing and the insights of this issue's contributing authors who live with a disability — Steven Hanlon, Audrey McGee and Chris Aubé. We are always indebted to them for sharing their experiences in **Communicating Together**. What I have appreciated especially in this issue has been Barbara Collier's introspection and her response to an important need. I hope many readers respond to the issues she raises, and I hope we can read their ideas in future issues of **Communicating Together**!

Lastly, I offer further fuel for thought following the reading of *Paul's Place* and consideration of the dilemma he raises regarding abilities. June Isaacson Kailes expressed the challenge cleverly and succinctly in her keynote address at the International Conference on Health, Aging and Cerebral Palsy, May 12-14, 1996, Toronto, sponsored by the Ontario Federation for Cerebral Palsy: The challenge is to know when to "use so as not to lose" and when to "conserve in order to preserve". We welcome ideas on this topic from our readers!

The Many Faces of Real Life: Confessions of a Clinician

BARBARA COLLIER



Barbara Collier

Barbara Collier is a speech-language pathologist with over 20 years experience working with adults and children who use augmentative and alternative communication. She has worked as director of the Adult Adaptive Communication Service, Toronto, as a consultant at the Augmentative Communication Service, Bloorview MacMillan Centre, Toronto (formerly The Hugh MacMillan Centre) and as a senior consultant of service development and training with the Ontario Ministry of Health's Assistive Devices Program. Barbara is currently an independent consultant offering communication services for both agency staff and individuals.

I was recently asked to present a series of workshops on safeguarding (protecting) people with severe communication problems from abuse and neglect. Needless to say, I went into total panic. In the 20 years I had worked as an AAC clinician in Ontario, I had never once been asked to address this issue either by an AAC user, a family member or another service

provider. Furthermore, it never dawned on me that I might have a role in supporting my clients in this area.

If I had stopped to think about it in my clinical practice (which I didn't) I would probably have assumed that AAC users got this sort of information and help from their parents, or maybe from one of the excellent transitional living programs in the province.

In preparing for the workshops, I tried to find out who was doing what in the area of safeguarding. First, I discussed the topic of safeguarding with a number of adult AAC users who used whole words, pictures or symbols to communicate. Without exception, they each reported their need for both vocabulary and training in this area. Some had taken a course or two with a transitional living program but reported that without the vocabulary on their displays and devices and without the time and support to discuss the topics, these courses were of limited value to them. Despite this need, each AAC user I interviewed, told me about incidents of abuse and neglect in his or her own life.

I then checked with some of my AAC clinician colleagues. With the exception of one clinician, none of my colleagues had focused on this issue with their clients.

I spoke with a number of transitional living services. They noted that AAC users who are literate and can independently use their AAC systems can and do take advantage of inservice sessions on safeguarding and other independent living topics. AAC users with more enhanced needs (indirect accessors or those requiring pictures or symbols) also

attend but do so without the vocabulary they need to discuss issues or without the partner support to communicate about the topic.

Finally, I went to the literature. I read everything I could find (which wasn't a great deal). But what I did read both shocked and appalled me. The incidence of abuse (physical, emotional, sexual and neglect) is reported to be two to five times higher for people with disabilities than for the rest of the population. How much higher still must it be for people who cannot communicate about incidents of abuse?

Riddled with guilt, I asked myself if I should have taught my clients about safeguarding. If so, what about other aspects of "real life"? What about sexuality, communicating with attendants, exercising human rights, etc.? Were these areas the responsibility of the AAC clinician, the family or the transitional living services? As an AAC clinician I am not an expert in any of these areas. On the other hand, professionals involved in transitional living training may not understand or accommodate the unique challenges faced by AAC users.

I now believe that, like the issue of literacy training for AAC users, these real life transitions for AAC users must be approached from a shared perspective. However, while I always used this team approach at the time when an AAC user was moving to a supportive living situation, I felt quite overwhelmed about providing information and support around safeguarding. My colleagues noted that given the mandate of their services and the waiting lists for them, there simply was not the time and in-house expertise to address this issue.

So who should be assisting our AAC users in these areas? To be fair, I always used a transitional living program with my clients when they were ready for it. At that time I worked closely with the AAC user and his or her attendants and trainers in transitional living. However, I tended to address issues relating to directing attendant services as the immediate and often the only need. I did not explore other topics such as safeguarding, human rights and sexuality. In many cases, I recognized the need to help users to exercise their autonomy as much as possible. Yet, in a clinical setting I did not have the time to deal with all of these needs. Given the scope of these issues and the lack of time to investigate or address them through my previous clinical practice, I am now trying to learn more about them and to offer services which I could not do within the clinical model.

Where do we begin in getting information and services related to safeguarding, human rights and sexuality to the AAC users, families and service providers who need them?

If I knew earlier what I am only beginning to become aware of now, I might have asked a set of questions which might in turn have influenced the outcome of my clients' service. For example, I might have asked:

What do AAC users need to know about the risk of abuse and neglect in their lives?

What vocabulary do AAC users need to both prevent and report abuse?

What do AAC users need to know about their human rights?

What vocabulary and skills do AAC users need to exercise their human rights?

What are the expectations, restrictions, and challenges involved in the consumer / attendant relationship?

What vocabulary and skills do AAC users need in order to take advantage of transitional living programs which teach consumers how to direct their services?

What linguistic and communicative skills and vocabulary do AAC users need in order to direct an unfamiliar person in their service routines?

What strategies are required by AAC users to communicate efficiently and effectively during their routines?

Can I redeem myself? Humble as it is, I have started to address my inadequacies. For the past three years, I have been working as an independent consultant and agency trainer, trying to address some of the gaps which I have mentioned above. I have been working closely with AAC users, attendants, agency supervisors and transitional living service providers. I have been researching, discussing issues and reading through back copies of **Communicating Together**. I have produced:

- *Communicating Matters* a videotape training program for attendants working with AAC users with enhanced communication needs. This video was funded by the Trillium Foundation. (See G. Verburg, **Communicating Together**, Vol. 15, 2, 1998)
- *See What We Say* vocabulary and tips for adult AAC users living in the community. This book is a compilation of words and practical tips used by AAC users in 20 community contexts. (See S. McNaughton **Communicating Together**, Vol. 15, 1, 1998)

This fall, I will be conducting a twelve-week course for AAC users entitled *Communicating with Your Attendants*. There will be a half-day session each week. It will be facilitated by an experienced AAC user and a speaking person who uses attendant services. The pilot course, which is funded by The Ontario Federation for Cerebral Palsy, will provide AAC users with vocabulary and opportunities to share practical ideas and strategies, practise in communicating within service routines, giving feedback to attendants, and handling challenging situations.

On the topic of safeguarding, I have given a number of workshops throughout the province of Ontario to service providers, attendants, clinicians and AAC users. These workshops were sponsored by Safeguards, Children's Services Training.

As a follow-up to these workshops, I will be giving a six-week (half day each week) course on sexuality for AAC users. This course will be co-presented with Susan Ludwig who has extensive experience in teaching sexuality to people with disabilities.

While all this is a mere scratch at what is needed, I feel that it is a start. Through my association with AAC users and transitional living service providers I have been fortunate to have been given a closer understanding of the needs of AAC users in transition. I also value what I have learned as an AAC clinician within the clinical service model in Ontario. I see an exciting opportunity to begin to bridge the gaps between the clinical world and the real world.

If you have personal experiences and information to share or you wish to obtain more information on any of the workshops or courses mentioned here, please write to **Communicating Together** or contact me at:

Tel: 416-778-5460

Fax: 416-778-5461

email: bbbc@total.net

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Preparing for the Real World

PETER MOORE



Peter Moore

Peter Moore was trained as a social worker. He worked as a protection worker with Children's Aid Societies and as an income maintenance officer and special agreements officer with the Ontario Ministry of Community and Social Services. He retired in 1995, and since then he has been employed as a consumer liaison with the Simcoe County Association for the Physically Disabled in Barrie, Ontario, Canada. In that role he provided resources and support to persons with physical disabilities in Simcoe County.

We thank Peter for sharing his perspective with our readers.

Each person, whether disabled/handicapped or not, has *potential*. We must attempt to come to grips with what we are realistically capable of achieving for ourselves. What are our expectations of ourselves? We must be realistic! What would

we like to do in our life — in education, employment, personal relationships? How can we be independent?

There is no easy answer. Two questions can be asked, however:

1. Do you know what your daily needs are?
2. How will those daily needs be met?

These questions apply whether or not the individual has a disability. Parents of a child with a disability must learn to prepare their child for the future. As I have talked with parents through the years, I have tried to remind them that they would not always be there for their offspring. It is critical for them to assist their child to become as independent as possible. They must be realistic in their expectations but assist their child in growing toward independence. The important thing is to encourage and support children to become “themselves”, not to aim for being “normal”.

As a consumer liaison working with physically disabled adults, I was recently asked to work with a committee of parents of physically disabled children. The mandate of this committee was to organize workshops for these parents to support them in their efforts to prepare their children for the future. As these children mature and become adults, they will experience a whole new life. When they leave home, they will be expected to think for themselves. When these children enter the adult world and leave home, they may live independently. They will be expected to make decisions for themselves. Much of this decision-making will relate to their

personal care. If parents do not encourage and support them to become independent while at home, this decision-making will be very difficult when they are living an independent life.

In all fairness to the child with a disability, the parent must encourage and support as much independence as possible. The child should be introduced to as many outside activities and support groups as possible so that when the child does become an adult, they will have achieved that sense of confidence and independence. It is imperative that families of children or adults with a disability come together to work toward encouraging and supporting independence for these individuals.

The Simcoe County Family Network defines the “Map of Normal Development” and the “Major Integrative Tasks for Adolescence” as follows:

1. *Autonomy*
Develop independence and self-decision-making.
2. *Sexuality*
Develop a positive self-image and self esteem — whether heterosexual, homosexual or bi-sexual. Just learn to be “yourself”!
3. *Relationships*
Develop mature relationships outside family: comfortable separation.
4. *Character Formation*
Develop a stable character, distinct from others.

5. Identity

Develop a sense of self as a unique individual.

6. Future Orientation

Develop plans for the future — “your future”.

As the consumer liaison, working with sixteen physically disabled adults, I circulated a questionnaire in the spring of 1997, to eighty consumers in the Simcoe County area. The questionnaire related to leisure and recreational activities.

Approximately 75% of these questionnaires were returned. Each consumer who completed the form was visited. We discussed their interests and this resulted in several of the consumers becoming involved in activities which they never thought they would ever be involved in — horseback riding, downhill skiing, sledge hockey, electric wheelchair hockey, educational and computer programs, and many more interests. As consumer liaison, I encouraged, supported and followed-up with all consumers, because I

realized and sincerely believed in their potential. It was a truly rewarding experience to encourage and support them to become the very best person that they could be! I believed in them, and pushed them to believe in themselves — a push to the finish line! At the end of the finish line, we are all winners in life!

The following is a Life Skills Checklist developed by Peter Moore and his colleagues.

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A Life Skills Checklist

- Knows home address and phone number.
- Knows or can find parents' business phone numbers.
- Has one friend to socialize with and to call in an emergency.
- Has phone access to someone in an emergency, e.g., hands-free phone.
- Knows how to call and whom to call for help in an emergency, e.g., neighbours, 911.
- Knows name of family doctor.
- Knows or can find number of handicapped transit.
- Can book transportation.
- Knows who to call for equipment repairs and supplies.
- Has an accessible emergency exit from house.
- Knows own bowel and bladder routine.
- Knows allergies and food restrictions.
- Knows own medications.
- Can prepare a simple meal, e.g., sandwich.
- Can do simple banking, e.g., withdrawing and depositing, cheque writing.
- Responsible for getting up on time — i.e. setting clock.
- Can make a grocery list.
- Can do simple grocery shopping with/without assistance.
- Has an allowance and knows how to budget it.
- Has assigned household chores.
- Is aware of birth control and has had sex education.
- Participates in purchase of own clothing and personal care items.
- Knows diagnosis and its implications and can explain this simply to others.
- Has a hobby or recreational outlet.
- Knows ways to deal with teasing.
- Is aware of street safety.
- Is aware of privacy and respect issues.
- Has and carries own identification.

The Right to Communicate in Real Life

GEORGE PIGACHE

George is a teacher at the Thames Secondary School in London, Ontario. He is responsible for supporting students in their integrated settings, specifically focusing on the transition years between high school and adulthood.

As we head towards the second millennium it would seem that the future for those of us with physical challenges is rosy. Our country has received an international award for the way it treats its citizens with disabilities. My province's government is moving on its election promise to pass the Ontarians with Disabilities Act. And technology is going to help those who can't walk and those who can't talk, to communicate at least all their Maslowian needs.

Unfortunately, I have very real doubts about the first two points in the above paragraph. In fact, when I really think about it, I'm not too sure about the latter two either. Actually we are making it possible for people with mobility difficulties to become more mobile. We have ramped buildings, better transportation and more machines to help people move about. We embrace the right to be mobile but do we really embrace people's right to communicate?

In North America we are experts at making products that do wonderful things, but do we really do wonderful things with them? Our microwaves mostly reheat, and our exciting cars mostly take us to the shopping mall. And so it is with most of our augmentative and alternative communication (AAC) equipment. It should help us access and communicate the wonders of each other's thoughts, but does it? We often complain about AAC, its glitches, how it is too complicated and expensive. Often this is so, but it is not always the case. Steven Hawking has been able to pursue and share his scientific ideas because of technology, and thousands of people have been able to express their basic needs through technology as they never could before.

Why is it then that I feel a profound frustration with the equipment, both high and low tech? Hawking is admirable and so is the equipment which enables him to communicate. But Hawking and his equipment do not work in tandem. Hawking worked out much of what he wanted to communicate before he required AC equipment. Generally, however, we are not spending much time developing young people's language as a means towards self actualization. We are using AAC primarily as a means to meet only basic needs. Once we have done this however, we often walk away having solved one level of problem not realizing that the AAC equipment itself is not going to develop language and communication skills.

At times I know I have commented that students I work with seem very self-centered. When I do this, I have to remind myself that this is likely because I have not spent enough time developing the language needed for them to reach out to others with empathy, or to reach into themselves to develop a more abstract way of thinking. Of course we believe in the right to communicate with each other as much as we believe in the equality of opportunity to reach one's potential. But often our actions don't demonstrate this.

I remember sitting with a team of fellow professionals trying to work out the communication needs of a student who was to die fairly soon. Our agenda was to find phrases to put on his communication book to help him ease his discomfort. We spent about twenty minutes on items we felt important — washroom, pain, food — while the student became more and more frustrated. He, of course, was at the level of "I want to talk about death" and we were at the level of "I want to go to the washroom". Now I don't believe that we were consciously denying the student the right to voice his real concerns and fears. This was happening, however, because we were not seeing his AAC equipment as being there for that purpose.

It is not that we spend too much time teaching people to use their AAC equipment to help them with activities of daily living. It is that we tend to do this to the exclusion of other needs that should be communicated.

I think this is happening for two main reasons. First, those who teach language and its uses, work separately from those who work with AAC equipment. Second, we are not committed to teaching all that language can do. Rather, we settle for the language of basic needs only. As important as this is it is not enough!

If we believe that we cannot develop our concepts and ideas without first having a language to create them, we cannot expect students with limited experience to be able to do it unaided. The result of this will be that many adult AAC users will be further removed from having the opportunities those who have the language for thought, criticism and self actualization will take for granted.

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The Real Worlds I Live In

ALDA STEPRANS



Alda Steprans

Helping Audrey and Steven spell out their articles for this issue made me very aware of the many real worlds I am surrounded by. Their memories of their first impressions of the hospital reminded me of the first time I walked into the cardiology ward of a hospital as a brand new student nurse. Everything seemed so odd and frightening. I kept expecting patients around me to have heart attacks and prayed that they would not realize that I had no clue of how to help them. I felt small and alone. What helped me overcome my fear, was coming to know the patients on the ward — getting to know the person in that hospital gown. When emergencies did occur, I couldn't help in the fashion the cardiac arrest teams on television did, but I soon learned how to get the help these people needed, and I could still care about them and their family members. The longer I worked there and the more I learned, the more I could truly help them. The day came when I was no longer scared and looked forward to going to work.

Even though I had already been a nurse for some ten years when I started working in the hospital Audrey and Steven live in, I went through many of the same kinds of feelings of helplessness I had experienced as that new student nurse. This hospital they live in is unique in that the residents it houses are really very severely disabled. I was not used to seeing a whole hospital full of residents who could not walk or communicate. Why was I so drawn to working there? I looked forward to going in to work, even though a part of me was very frightened and in a sense helpless. How could I help these people?

It did not take long to understand that what kept me really interested in this hospital was the stories of the residents' lives that I kept learning in little pieces from visitors, family members, other residents and nurses. I learned that behind each face was a very special unique person, who had a special past and was working toward a future, even though that future might differ from the futures that people outside the hospital's walls work toward. My biggest pleasure has been in helping some of

these people accomplish the goals they have set for themselves. Some of the residents do get out into the other real worlds outside the hospital, but they have come to appreciate some of the advantages of living in the real world the hospital walls provide. Without the specialized protection and assistance these walls offer, many of those inside could not survive. Many of these people still have many gifts to share with those who get to meet and listen to them. When people have difficulty expressing themselves, each word they say is carefully thought out and often very special.

There are surely many other real worlds out there that I have not been exposed to, in which I would have to learn much to survive or do well. I hope I will have the courage to enter them if opportunities arise. I often realize that for many of the hospital's residents, the opportunities to see other real worlds are limited — partially by finances, partially by lack of will/imagination/energy of the world around them. But that again is the case for many people all around our world, isn't it?

§

New Rates for Communicating Together

(starting with the Winter issue, 1999)

	ISAAC Members	*Non-ISAAC members
Canadian	30.00 Cdn	35.00
US	28.00 US	33.00
International	34.00 Cdn	40.00

Rates for consumers, students, seniors

Canadian	25.00 Cdn
US	23.00 US
International	30.00 Cdn

*For ComTog Online, Non-ISAAC members add \$5.00 to above rates.
No added charge for consumers, students, seniors and ISAAC members.

Steve's World

STEVEN HANLON

The real world is the one here at the hospital I live in. What prepared me for this real world is that I'm easy-going. My mother and father taught me to be like that. All my brothers and my sister are easy-going too.

School helped me too. I was an average student, but I did really well in sports. Being good in sports

helped me to cope. Sports teach one that you win some and lose some but it's how you play the game that's important. I always play dirty — ha, ha. I loved rugby and hockey, soccer, track and field, too. I rowed like my grand-dad, Ned Hanlon. He taught me to row a little bit. I was little when he died. My dad taught me how to drive.

Some people don't think of the world in the hospital as normal, as real. They all think we're crazy in here. I am a little crazy. I cheat a lot

when I play games downstairs or dominoes with Audrey, but I'm happy.

I am expected to act normally, but I can also be myself here. Everyone accepts the fact that I cheat. There are few secrets here. When I first came here to live I thought a lot of things were not normal. In fact, everything seemed abnormal at first, but it was hard living outside the hospital. This is a better place for me. Now, everything seems O.K. and normal.

§

My Real World

AUDREY McGEE

I remember when we first met Audrey, a year or so after she had had a major stroke that took away her speech. What an unhappy, frustrated soul she was. But over the course of her first year living with us she changed enormously. For the most part, she is a very contented great-grandmother, taking joy in all the people around her. We gain a lot from her and her attempts to continue learning and teaching us.

This is what Audrey has to say about her Real World.

My education was too formal. I started to work after second form and then took a business course. None of that prepared me for the real world. As long as things were O.K. it didn't matter. I can't think of anything that could have prepared me for what I have been through since I had this stroke.

I had good jobs and worked in a bank. My job taught me that being flexible was an asset and that I could keep on learning — always. I also

learned to respect all people. All of those things have helped me through life.

In the hospital that I live in, I continue to constantly learn. I have learned to appreciate the arts, like painting. The art class here is terrific and I really enjoy trying to express myself through painting. Barb, the occupational therapist here, is trying to get me hooked up to e-mail in the hospital. That might open up a whole new real world for me. I will also possibly be going to the Aphasia Centre soon. That is exciting, because I love to learn new things.

I just got a new electric wheelchair. That gives me a lot more freedom and more opportunity to participate in the real world, both the real world within the hospital and that outside its walls. I am still a little afraid to go across the street in it. I'm still frustrated by a lot of things I can't do. I loved to knit, but I can't do that anymore because I can't hold the needles. Still, I'm busy all the time doing things I can do.

I've learned to accept the fact that my ability to move and talk might not get any better. Life here in the hospital does have its problems, but so does life everywhere. I really hate week-

ends here. There is so little to do when all the activities, physio, and occupational therapy departments are closed. There are fewer volunteers and visitors around as well. That's when I feel lonely.

When I first came to the hospital to live I was scared. This world didn't seem real. I was afraid of everything and everyone. It was hard not being able to talk. It took a long time to get used to things here. I slowly learned that this place was likeable. People here love me. That makes all the difference.

One of the advantages of living in this hospital is that I feel loved and respected. In the real world outside there is an awfully big rush and lots more impatience. Here I have all the freedom I need. The disadvantage is that no matter what I do, I cannot walk or talk. I am expected to behave normally here, to be polite and patient, but I can also be myself and be angry or sad, when I feel that way. Safety is a big issue in the hospital. Many of the rules here are for my safety or for the safety of other residents, who are even less able to do things for themselves, than I am. These rules are sometimes annoying, but they help me feel safe!

§

Real Independence: a Peek into Part of Chris Aubé's Background

GEB VERBURG



Geb Verburg

Chris Aubé is a twenty-one-year-old young man who is attending Northern College of Applied Arts and Technology for the first year. He uses an AAC device and a powered wheelchair and has great plans for a career in World Wide Web (WWW) design and development. I want to tell a little story about him.

In 1982 I was part of a study in which two to five-year-old youngsters were given a wheelchair that looked like a go-cart and that we called the MPV (for Miniature Power Vehicle). Christian Aubé was one of ten subjects enrolled in that study. He got his cart, was given driving lessons and returned at three month intervals to the centre to be tested both for driving skills but more for changes in physical, perceptual, motor, self

help, and academic abilities. The study showed clearly that providing powered mobility at this (for that time) early age was not only possible, it actually enhanced all the measurable skills and many others that we could only assess anecdotally. In contrast to the wisdom of the times the young children who participated in our study were shown to be very capable and responsible drivers and did not damage either their parents' homes, their schools or their siblings. Statistically significant changes in physical motor, perceptual and academic performance were observed, but much more interesting were the anecdotes about participants. One of the subjects learned to use four point crawl when her cart was not available.

Christian was the source of two memorable anecdotes. I am telling them here as an enhancement and counterpoint to his praise of communication technology. On one of the return visits to the centre Chris's mother was visibly upset and had a story to tell. The Aubés lived in Timmins, Ontario in a suburb. A few days before the appointment at our centre (Bloorview-MacMillan), Mrs. Aubé was busy in the house when she received a phone call from her sister-in-law who lived about fifteen minutes from her place. Her sister-in-law asked her where Chris was and she said: "Well, he's in the yard, of course." To which her sister-in-law responded, "No he's here with his girlfriend." Chris was four-years-old then. He had decided to go visit his aunt and had recruited the help of his

friend from next door to ring his aunt's door bell. Chris was in his MPV, his girlfriend was walking. The two managed to negotiate the streets (including one large street with boulevard in the centre) safely, and upon arriving at the aunt's house rang the bell. When the aunt asked Chris, "Where is your Mom?", he said, "Home". Both his aunt and his mother felt it had been a dangerous expedition and that something ought to be done to prevent a recurrence.

When I heard this story I could still sense the emotions on Mrs. Aubé's part. She was in a quandary. Chris loved his cart but could now also use it to do dangerous things. Should she limit his movement or roaming privileges? I pointed out how fantastic I thought the trip had been. Planned and executed flawlessly (as far as we knew), showing all signs of an independent and entrepreneuring pair of children. I felt that it was a wonderful way of learning for Chris and that he obviously had been as careful as necessary to manage to complete the trip safely. Furthermore, he probably would not have been allowed to go alone with his friend if he would have asked.

I believe that that incident and the positive interpretation of the trip has helped Chris to become more independent. Equally important it helped Mrs. Aubé to let go of him a little more so that he could develop the independence which in turn has brought him to the point he is today. Thank you both for helping me learn and for helping me with this article. §

My Real Life

CHRIS AUBÉ

Blissymbolics, an easy word that means a lot. Bliss stands for Beautiful Living Is So Simple. It means that this method of communication gives a way of expressing their needs to people who are physically disabled, therefore getting these people through each day of their life.

When I was a baby, I would cry all the time not being able to express my needs. This all changed one day when a lady introduced Bliss to my parents. They started by putting huge flash cards of Blissymbols on everything in the house so that I would begin to recognize each symbol and realize that by pointing to these symbols I could communicate my needs. When I was old enough to write, I started using an alphabet board and I would spell everything I wanted to say. Then, I progressed to a voice synthesizer which I presently am using. This is all thanks to Blissymbols which enabled me to make people realize that in spite of my disability, I too could communicate.

Communication — What is it?

To most people it is a way of expressing themselves verbally. But communication is also non-verbal, even if this way of expressing oneself is not comprehended by many people. When someone has a speech impairment he or she has no other choice but to use an alternative method of communication — Blissymbols, body gestures, signs language, voice synthesizers, etc.

Many alternative methods of communication helped me to express what I needed throughout my life. None of these was my own voice; however, I managed to express myself just the same because people took the time needed to communicate with me no matter which method I used. I cannot imagine what my life would be without having a method of communication. Maybe I would have been in a bed all my life because not being able to communicate might have meant that people would have treated me like a person who was mentally challenged. Maybe the world would be tired of hearing me cry all the time. Instead I graduated from high school and I am starting college.

The next time you see a person with a handicap using an alternative method of communication, talk with that person. As you will see, those who use any method of communication other than speech are very intelligent people who have something to say. After all, these people were wise enough to learn how to use an alternative method to communicate and most of these people started communicating using Blissymbols. They were invented by Mr. Bliss so that every nation could use the same communication method. His hope was that Blissymbols would solve the main problem that is causing most wars — lack of understanding of one another. §

SYMBOL SOFTWARE

by
**Sally Millar
and
Janet Larcher**

available from:
**Sharing to Learn
Suite 215,
304 Stone Rd. West,
Guelph, Ontario,
Canada N1G 4W4**

\$58.50 Cdn.
(This includes GST
and mailing charge.)

\$45.00 US
(includes mailing charge)

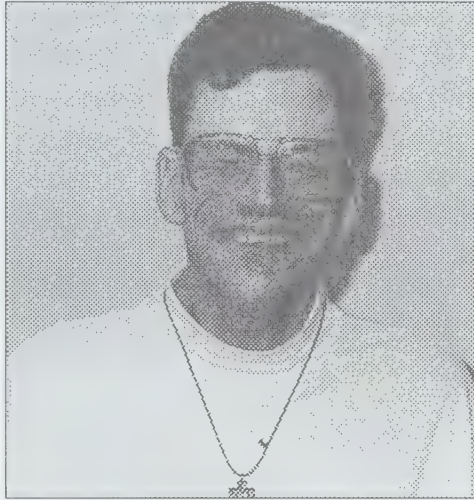
Kathrin Talks with Her Eyes

available from:
**Prentke Romich Co.,
1022 Heyl Road,
Wooster,
OH 44691 USA.**

Orders should
include payment of
**\$8.00 (US) or
\$11.00 (Cdn)**
to cover cost
of book and postage.

Co-independence and Independence

PAUL MARSHALL



Paul Marshall

As I look back over my life, I always had an inner drive to be as independent as I could. I am not sure where we get our inner drive to do or not to do things. In my case, it is *not* an ego trip or "I will show them" (well, maybe a little!) frame of mind. It is just that I enjoy doing things for myself even if I have to struggle and put more energy into a task. This can be good but as I am learning, it can also be a bad thing.

I think it is human nature to want to survive no matter what the cost. Not one person is the same, we all have different needs, different degrees of drives that push us and really make us into the individuals that we are. I know myself, I have my good points and at the same time I have many faults. This is a part of life. We all have good and not so good points. All too often it seems

our bad points come out and act as negatives when we want to hide them.

The theme of this issue is the Real World. As I think about the *Real World*, I wonder if I want to be in the mainstream of living life, trying to measure up to the values that really don't have much meaning for me. Do I want to be out there in the large playing field where the balls come at ninety miles per hour? Or should I be happy playing on a smaller field, holding a bigger bat, where the balls come at a slower rate? I am deeply concerned that we as a society are telling people with disabilities that you have to live and *play ball* on the main field. More and more I am realizing the main playing field is nothing but a big myth that drains energy and prevents us from seeing clearly. What is so wrong with living a different lifestyle, or doing without the *Real World* and all its trappings?

**Do I want to be out there
in the large playing field
where the balls come at
ninety miles per hour?
Or should I be happy
playing on a smaller field,
holding a bigger bat,
where the balls come
at a slower rate?**

I live a very busy and I think a very rewarding life. To me, it doesn't matter whether I am on the

big playing field or not. I am not saying if a person with a disability *can* function in the *Real World*, they shouldn't reach for it and enjoy all its benefits, if that is what they want as a person. At the same time, we must realize that having a different life style is OK. I think we get too wrapped up in our thinking with a mindset that the *Real World* is where we have to be. I can remember when I was spending my days helping out on the family farm. A few people came up to me and said I wasn't living in the *Real World*. For the life of me, right up to now I didn't understand that statement. It blows me away to think if we aren't in the mainstream of living life that we can't feel the bumps and highs or lows. To me, the *Real World* is a myth because life has too many factors that alter one's lifestyle. When you think about it, the basics of life can be wrapped up with eating, sleeping, finding some enjoyment, having some reason or reasons for *being*. When we look at this, we can see there is not much difference between a ruler of a country and a person who is born with countless limitations. We all have 24 hours in our days. We just have to take different paths.

So much of dealing with things is how we react in our mind with circumstances. An example occurred, just last week. I was going to work at the Bloorview MacMillan Centre. At the Toronto bus station, I was getting a taxi. Most of the drivers know where I go. I overheard a driver telling my new driver, "He goes to that hospital where these guys go." Now, rightly so, he doesn't

know me from the dozens of others with some kind of disability but it is very often that we all get dumped in one basket with one label that says "disabled". This is the *Real World*. No matter what we are capable of doing, we will always be looked upon as being *disabled*, and we will carry the baggage of the mindsets that come with this label.

This summer my mom, my cousin and I were blessed to go to Ireland, and take a two-week bus tour before the ISAAC conference. When we first got to Ireland I fell and did a number on my hip, we thought. Really it was my lower back. For the three weeks I was in quite a lot of pain to say the least. I was using a wheel chair a great deal, which I am not used to. For the two weeks leading up to the conference, I was hoping that I would be much better so I could function largely on my own. Well I wasn't, and it turned my trip into one where I learned a lot about dependence. I am not going to put much of the details in because in my mind there is no benefit in doing so. What I learned during my time in Ireland was: (1) I had many persons who really care about me there, reacting to my circumstance, (2) I was wondering if I should go home with my mom and miss the conference, but knowing all along the reason I was there outweighed my leaving, (3) I was in pain and out of my environment overseas.

Now let's view this as a *Real World* experience. I had people who knew me worrying about me and I had people from the conference trying to do their very best for me. I am sure the dynamics of each individual's actions, thoughts and even everything that goes into relating to one another, if included, could fill

this issue of **Communicating Together**. This is being out in the *Real World*.

We have to learn and keep learning how to relate with people in all kinds of circumstances. I think this is the key beyond any other. If we can learn how to read and react *rightly* to people then we are on our way to a very healthy lifestyle. When I say that I badly fail at this maybe I am being hard on myself. I know if I step back and think about what is really happening, or maybe I should say what is really important, then I can react in a way that is proper. I believe deeply there is a big gap in how an AAC person relates to people and how people relate to us that we haven't even started to touch on or to understand. I really want to do an article at some future date on this.

**The greatest level
of independence
is knowing
at what level you need help
and asking for it.**

I want to quote Shirley McNaughton and what she said to me this summer while we were in Ireland for the ISAAC conference. She said, the greatest level of independence is knowing at what level you need help and asking for it. These are very wise words for anybody to hear, especially if you have any form of disability. It is vital for me as a disabled person to know when my capabilities (or lack of capabilities) might lead me to an unnecessary dependence on others. I

need to know as well when I may be hurting my body if I remain independent. Sometimes it is good to allow people to take over and do things for us because when it comes right down to it, they need to, and it gives us time when we can restore some energy. If we or I just let them do it, the whole event goes simpler and much easier. However, there is another point where our dependencies become a source of *disempowerment*. I know this line is always moving, and that is the fun of trying to pinpoint where the "don't cross" lines are. We should realize there are times when if we don't ask for help, we are contributing to our own disempowerment rather than if we ask for a bit of help which is the highest level of independence.

If we want to be prepared for life in the *Real World* whatever this means, it is vital for us to understand and know the limitations of our bodies and mental well-being. It is also vital for us to try to read and understand what is happening around us. The aging process may or may not change our abilities. Something that has been on my mind lately is, how the outer circumstances of our lives change from day to day. If we can listen and even live with our inner person without being swayed by what is going on around us, then we will learn to be a vital member of *our own* "Real World". §

**Have you
Moved?**

**Please send us
your new
address.**

Insights into Three "Real" Worlds

SHIRLEY McNAUGHTON

Three books have come across our desks that are relevant to the theme of this issue. Each provided an interesting but different insight into the Real World.

Symbol Software

by Sally Millar & Janet Larcher

Symbol Software is published (1998) by the CALL Centre, (Communication Aids for Language and Learning), University of Edinburgh. Its authors bring extensive experience to their topic. Sally Millar is a speech and language therapist specialising in AAC in schools, a Research Fellow at the University of Edinburgh and Joint Coordinator of the CALL Centre. Janet Larcher is an independent consultant specialising in AAC and technology for children and adults with special needs, based in Weybridge, Surrey.

As described by its authors, this is a resource book for people who:

- know lots about symbols but less about computers and software
- know lots about computers and software but less about symbols
- know lots about symbols and software who will find it useful to have information presented in one place
- are new to symbols and computer software.

Following a brief overview of *Blissymbols*, *COMPIC*, *Dynasyms*, *Makaton symbols*, Mayer-Johnson *Picture Communication Symbols* (PCS) and *Rebus symbols*, a section is devoted to reviewing the various groups that use symbol systems:

- (1) as a means of communication and expressive language for children and adults with severe speech difficulties,
- (2) as a means of communication (both receptive and expressive language) for children or adults who have severe, profound, complex or multiple learning difficulties,
- (3) as a support for language and literacy learning for very young children, and for children with severely delayed or specifically disordered speech and/or language (including children from bilingual or non English speaking families),
- (4) as a supportive bridge to literacy, for people of any age who have difficulties using ordinary written text (who may or may not have speech and language problems).

The symbol software that is described in this publication is divided into two main types: *Symbol*

Libraries (sets of symbols stored digitally) and *Symbol Programs* that support access to learning and the curriculum. The latter are described under four sub categories: Utilities, Development of Language and Literacy, Communication Aid Programs, and Special Access Programs.

Software is reviewed as to:

- (a) the platform it runs on and system specifications,
- (b) ease of installation,
- (c) usability,
- (d) product features.

Tables summarizing the information and pictures of screens are generously provided. Sections follow relating to Choosing and Using Symbol Software, References, and Resources, including web site addresses for 17 software programs.

This book is an excellent resource re current symbol software. I highly recommend that you purchase it now if any of the above reader criteria apply to you. Changes occur quickly in software. It is hoped that the authors will make ongoing updated versions readily available to the field. §

Symbol Software is available in Europe from the CALL Centre, Fax: 0131 668 4220, email: call.centre@ed.ac.uk

For ordering in North America from *Sharing to Learn*, see the announcement on page 14.

Their Manner of Speaking

Anne Warrick and Sudha Kaul

Their *Manner of Speaking* is published (1997) by the Indian Institute of Cerebral Palsy, Spastics Society of Eastern India, Calcutta. The authors bring to their subject over 25 years of experience working with children and young adults with multiple disabilities. They also bring their collaborative experience of the past 15 years in introducing AAC in India.

Their Manner of Speaking focusses primarily on face-to-face communication. It begins with information relating to AAC, its philosophy, terminology, methods, and population of users. There are chapters relating to assessment, vocabulary selection and representation, making communication boards, planning lessons. In the section relating to where to begin, the Participation Model (Beukelman & Mirenda, 1992) is introduced and illustrated using two case examples. Barriers to opportunity and access are described and problems are identified. An example of a school

lesson plan (re Garden/Planting) is presented in which there is a focus on augmentative communication. Sample displays are included and a rationale is given for the recommendations. The last chapter is comprised of the writings of AAC users, their parents and their teachers, accompanied by photographs of the AAC users.

The format of the book is that of a self-study programme, with review questions and references for further reading at the end of each chapter. Appendices provide a list of AAC Resources and Materials and examples of student record forms, examples of displays, stages in development of Hindi language and of English language, and a glossary of terms.

It is exciting to see a book dedicated to communication programming for Asian AAC users. I particularly enjoyed seeing the adapted picture symbols for Bangali and Hindi users, and the examples of non-English word boards. The illustrations by Bela Purohit provide

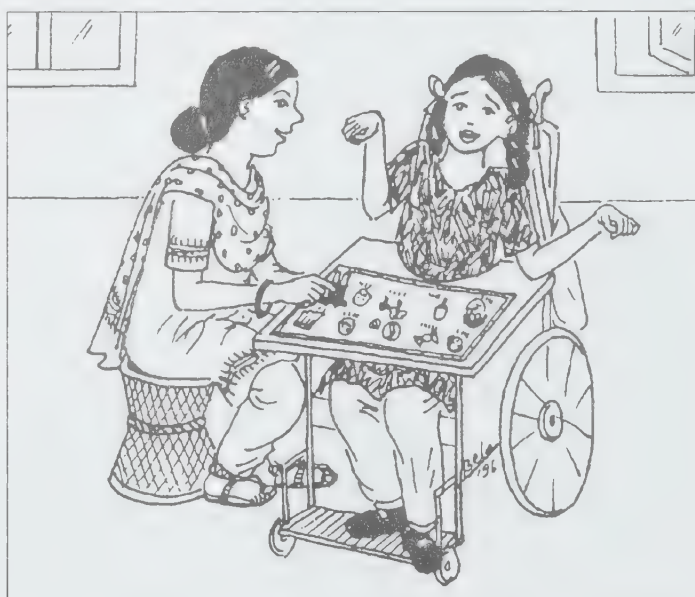
a wonderful way of making this book belong to Indian speech-language pathologists, teachers and parents. Anne Warrick and Sudha Kaul are to be congratulated! They have provided the AAC field with a valuable resource. The book has particular relevance for people working with Asian populations, but offers a good foundation to any newcomer to AAC.

Information to order *Their Manner of Speaking* can be obtained from Indian Institute of Cerebral Palsy, Spastics Society of Eastern India, P-35/1, Taratolla Road, Calcutta 700 088, India. Phone: 478 3488/478 4177.

Reference

Beukelman, D.R., & Mirenda, P. (1992). *Augmentative and alternative communication: Management of severe communication disorders in children and adults*. Baltimore: Paul H. Brookes Pub. Co.

§



Kathrin Talks with Her Eyes

Kathrin Lemler and Stefan Gemmel

with illustrations by
Astrid Leson

K*athrin Talks with Her Eyes* is published by Verlag Butzon & Bercker, Kevelaer, Germany, in cooperation with Josefs-Gesellschaft e.V., Koln, Germany, a catholic organization that supports disabled persons. The original book was written in German, but an English version is now available. It tells the story of ten-year-old Kathrin's life. The many things she enjoys doing as well as the many things that are difficult for her are told in the first person. The illustrations are excellent. They remind us that Kathrin has severe communication and physical impairments, but the beautiful colour

presentation shows a young girl full of energy and life. Kathrin may be nonspeaking, but the book shows she has a lot to say! As the back cover describes, "Kathrin's story shows that a child with disability has wishes and dreams and finds pleasure in life just like every other child."

I had the pleasure of selecting Kathrin Lemler, Stefan Gemmel and Astrid Leson as the recipients of the *Shirley McNaughton Exemplary Communication Award* for 1998. At the ISAAC Conference in Dublin, I presented three plaques to Kathrin's friend, Paul Andres, who in turn presented them to the three recipients at the Annual Meeting of the ISAAC

German Chapter in September. Much thanks must go to Christof Bink who nominated the authors of this book for the award, and who worked hard to ensure that an English version of the book would be ready in time for the ISAAC Conference in Dublin. Many conference participants were able to purchase a copy of this charming children's book. Now it is available in North America through the kindness of the Prentke Romich Company. (See announcement on page 14.) *Kathrin Talks with her Eyes* makes a wonderful gift for children of all ages interested in reading about the life of an AAC user.

§



Kathrin communicating

Whose Real World?

SHIRLEY McNAUGHTON



Shirley McNaughton

In the Summer, 1998, *Paul's Place*, where I was guest author, I promised to have more to say in the Fall Issue regarding BlissInternet and the support it offers toward literacy acquisition. In considering the themes for this and the next issue, however, I decided that I had pressing thoughts to share regarding Preparing for the Real World, and that I would defer expanding on my discussion of Bliss and Literacy until the Winter Issue, with its more fitting theme, *Community Partnerships and Volunteer Involvement*.

During our annual Associate Editor planning meeting, as we expressed our concern about the inadequate preparation young AAC users were given to equip them for the real world, I am sure most of us were referring to the real world of society — recognizing that there were many challenges to be faced,

and believing that preparation was the key to meeting those challenges successfully. I now wonder, however, if the theme as stated, isn't leading us in a direction that itself should cause concern. Are we not inferring that there is one "real world" — that of the general population — and that our task is to prepare AAC users for it? In so doing, are we not losing sight of the different real world of AAC users?

There is nothing like travelling away from home to remind oneself of the real world of the general population! The recent 8th Biennial Conference of ISAAC (International Society for Augmentative and Alternative Communication), held in Dublin, Ireland, August 24-27, provided an excellent case in point. The campus of University College Dublin, where the conference was held, was a pleasant and inviting site for those of us who were able-bodied. The daily challenges it presented to AAC users, their assistants, friends, and the conference organizers, however, made the contrast between the real world of the general population and that of persons with severe physical and speech impairments strikingly evident. The different requirements regarding time, transportation, communication, and accommodation often led to clashes between the two worlds. Yet both worlds are real — that of nondisabled persons for whom the world is filled with independent, fast-paced activities and that of persons with severe disabilities for whom life must be more slowly paced, special arrangements must be made, there is a heavy reliance on technology, and often activities can only be undertaken with assistance.

Everything that could be done at the ISAAC Conference to accommodate the disparity between the two worlds was done. Often this required extensive effort and additional expense (attendants, hotel arrangements, special transportation, etc.) As I watched special arrangements being made to meet the needs of those with disabilities, I could not help but compare the conference situation in which the gap between worlds was concrete and obvious (and dealt with), to the wide divide that exists in the communication/language/literacy "worlds" between those who speak and those who use AAC. The less concrete, less obvious differences between the two communication/language/literacy worlds, renders this domain more at risk for being overlooked. It also means that more knowledge and more effort is needed in order to deal with it! There, at last you know why this article is appearing in *SymbolTalk*!

An excerpt from an excellent new resource book, *Symbol Software*, Millar & Larcher, 1998, (see review on page 17) demonstrates the chasm between the two worlds when it comes to symbols. In responding to the question, "Which is the best symbol system?", Millar and Larcher first quote the factors that were enumerated by me at the 1990 Bliss International Affiliate Meeting. The two authors follow my list with a set of factors they have observed in the real life of schools, day centres and clinics!

Ideally the symbol system selected should:

- encourage cognitive development;
- encourage language comprehension;
- encourage social development;

- be acceptable to family, friends and community;
- have grammatical structure;
- have sufficient vocabulary for user's needs;
- be generative and expansive;
- have logic to facilitate learning;
- be motivating to use.

(McNaughton, 1990)

Under the *pressures of real life in schools, day centres and clinics* [italics added], other forces too may come into play in the decision-making process. The truth is that choices may be further influenced by the fact that a certain symbol system may be one that:-

- the teacher or therapist already knows;
- the school, centre or region already supports;
- can be easily printed out on the kind of computer the school, centre, etc. already has;
- uses the cheapest software/computer;
- uses the software that is easiest & quickest to learn and user;
- has attractive, easily obtainable and cheap accompanying materials.

(Millar & Larcher, 1998, p. 15)

There we have it — the two worlds! The first looks to the learning needs of AAC users if they are to develop their full potential and live optimally in their personal real worlds. The latter looks to the real world of the larger society that places funding, training and staffing limitations upon those who provide service and education to AAC users. So, which of the worlds is the one for which parents and educators should prepare young AAC users?

Of course, there is no single simple answer! It is not necessary to live exclusively in one or the other. Perhaps our question should be one relating to balance — to what extent should a particular individual attempt to live in society's real world and to what extent should he or she attempt to live in a personally adapted real world? Many members of the deaf community have striven for decades to be allowed to live in their own language world. They have demonstrated through their determination and accomplishment that there can be great value in maintaining a sign language world.

Within the graphic domain, I believe a balance should be sought for each individual. There are two critical elements that we would do well to consider.

1. Don't forget there are options.

First we must recognize that there are choices that can be made. There are alternative graphics that offer different capabilities to their users. The different types of graphics and the capabilities they afford should be well considered. Hopefully, primary attention will be given to the needs and abilities of AAC users so they can achieve their highest level of performance within their personal real worlds. That means the list of "ideal" qualities should be carefully examined by each AAC user and their family. Whose life is it anyway?

Of course, the real world of clinical service and education cannot be ignored. But we must remember that most of the clinicians and educators working in this world are

there because they want to see the best done for AAC users. The pressures of their world and sometimes their limited knowledge of alternative symbol systems, can make it difficult for them to accommodate to the personal real world of an AAC user. But here is where the role of the parent or care giver becomes so important. I saw the advocacy role in action many times during the ISAAC conference when it came to physical arrangements. Reminders and offers of help were needed to ensure that the necessary transportation, meal, accommodation and scheduling arrangements were made. So it is in the communication, language and literacy world.

Reminders and offers by parents and caregivers to share the responsibility for communication, language and literacy learning are needed. For accommodations to be made in and by the real world of clinicians and educators, there must be the strong involvement of persons who know the real life situation of the AAC user. Only then can the AAC user realize his or her full potential — living in a real world that maintains a balance between the individual's and society's needs. Our goal must be to acknowledge the needs of AAC users in their communication/language/literacy world as much as we do in their transportation/accommodation worlds. And symbols are an important component of the communication/language/literacy world. The second list above, that describes so well the real world of service delivery for many AAC users, does not have to dominate decision-making. It does, however, have to be recognized and

dealt with. This is where the involvement of family and friends comes in.

2. Don't forget the importance of "helpers".

The contribution to be made by parents, caregivers and volunteers cannot be underestimated. Preparation for the real world of the AAC user depends upon how much support he or she is given in developing a unique life direction that places the needs and abilities of the individual AAC user first. This can be done when individuals are assisted by those who care about them. It is an awesome reality — the real life actualization of AAC users is determined by those in their lives who care for and about them and who advocate on their behalf. As adults, we hope many will advocate for themselves, but as children at the beginning stages of communication, language and literacy development, the achievement of their potential depends on others. Preparing AAC children for their real world, from a communication/language/literacy perspective means enabling them to achieve their potential. This includes ensuring they have the symbol system that provides the opportunity for the most growth. Symbol advocacy should strive to ensure that those who are able to attain a level of literacy that enables them to explore the world by reading the books they wish and travelling the internet as they choose, do so. For those who are unable to attain this level, symbol advocacy should strive to ensure the highest level of competency with the highest level of system achievable by the individual is always being worked toward.

I find myself continually returning to the advice we gave throughout the seventies and eighties: examine each symbol set or system and ask what learning opportunities it affords. In the context of this issue's theme, there is a further question to be asked as symbols are evaluated: "Whose world are the symbols supporting — the users' or the instructors'/service providers'?"

And don't forget we now have the world wide web as an added resource for advocates to get their information independently. As starters, you could check out the following:

Blissymbolics

<http://home.istar.ca/~bci>

Discover & Icon Galleries

www.donjohnston.com

PCS

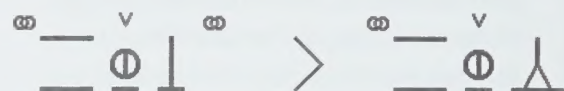
www.mayerjohnson.com

Widgit Software

www.widgit.com

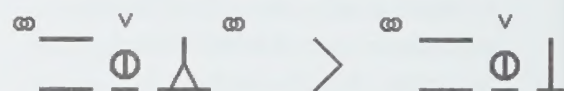
I returned home from the ISAAC Dublin Conference, humbled by the long road yet to travel in adapting society's real world in order to accommodate it to the real world of AAC users. There are so many residences, vehicles and public buildings to make accessible, so many attitudes to change. But I was excited about the technological developments (see *Symbol Software*, p. 17) and the growing graphic knowledge within the AAC field. Both are making the software world more friendly to AAC users. Real choices are possible! Watch for the announcement in **Communicating Together** in 1999 re the Proceedings

from the ISAAC 1998 Research Symposium, to be published in book form. This forum gives a glimpse into the research questions being asked. There is a growing wealth of resources available to help AAC users and their advocates. The Millar and Larcher book is one excellent way to discover them. Let's ensure that the real world balance is weighted in favour of the AAC user, that is:



"World that's real for the person
having stronger weight than world
that's real for the citizen."

NOT



"World that's real for the citizen
having stronger weight than world
that's real for the person."

We must always keep asking, "Whose real world are we really preparing for?" Let's put as much energy into achieving a balance between the individual's and society's needs in the communication/language/literacy world as we do in the world of transportation and accommodation. And let's remember, there are symbol choices to be made!

Reference:

Millar, S. & Larcher, J. (1998). *Symbol Software*. Edinburgh: Call Centre, University of Edinburgh. §

REMEMBERING MARTYN

Martyn Humm

Mar. 21, 1962 — Nov. 5, 1998

ANNE O'MALLEY

—2! 1 1♡+!

quiet helping friend

*While we were in the final stages of preparing **Communicating Together**, we learned with sadness of the death of Martyn Humm. We re-arranged our copy in order to include our tribute to Martyn. As you will see from the reminiscences that follow, Martyn was a much loved and admired person. All of us who knew him will remember him fondly.*

*We asked Anne O'Malley, life skills counsellor at Participation House Brantford, to share with our readers the things that Martyn's friends there remember about him. As well, we are re-printing the poem that Martyn's brother, Nevel, wrote which first appeared in the June, 1996 issue of **Communicating Together**. I met Martyn when I was doing the research for my doctoral program. Typical of Martyn, I had to seek him out, as he did not come forward when I asked for participants. When I began to have time alone with him, I discovered a kind, intelligent, humble person. I thank Normand Pellerin, for telling me to look for Martyn. Normand knew Martyn in the seventies, when Martyn lived in Rideau Regional Centre, an institution that housed over 1,800 persons. Martyn spent his childhood without formal education. He was one of the early children to demonstrate how bright they really were, by the way in which they used their Blissymbols. I will always treasure my time with him!*

Shirley McNaughton

From Martyn's friends at Participation House Markham

Martyn Humm lived with us for eight years. He just recently moved to Freeport Hospital in Kitchener for health reasons. Martyn was an important resident of Participation House. He participated on the Residents' Council, the Clients' Council, and represented all residents at our annual telethon one year. But more than this, Martyn was our friend! When I met with the residents of PH to discuss doing a tribute to Martyn, three words were frequently used — quiet, helping, friend.

Valerie Cruse has known Martyn the longest, as she also lived at Rideau, and knew him there as well. She says, "Martyn was a very special person to me, and very, very intelligent."

Roberto Colautti moved to PH a few years ago, and is now married to Bonnie, another resident of PH. Roberto says, "When I got engaged, Martyn planned an engagement party for my wife and me. Before he moved from PH, he had been very sick."

Andrew Nielsen also lives at PH. He says, "I tried to help Martyn when he got his G-tube, because I have one. I think of Martyn when we have outings. Martyn always forgot to bring his foot pedals and his feet would hit the floor."

Paul Sullivan has lived at PH since it opened. Paul says, "Martyn was my room-mate and friend. He asked to be my room-mate. He already had a G-tube and he knew I was getting one. He wanted to be a support for me as I went through this."

Jeff Miller is our van driver/resident care counsellor. Jeff says, "Martyn was the first person here to vote. This symbolizes Martyn to me."

As for me, Anne, "When I think of Martyn, I hear his laugh, I see his smile, and I feel his love."

Martyn, you were with us at PH for a short eight years, but you will live on in our hearts and memories forever!

—2! 1 1♡+! *

We will always love you!

To My Brother

Together we shared a child's world.
We talked, we disagreed.
We shared personal hurts and joys,
And the older we grew,
The stronger the bond between us became.
I was always so proud to have you as
My brother.

Now Life has taken us down separate
Paths, but your well-being and happiness
Will always be foremost in my thoughts.
Neither the span of miles nor years
Between us can ever change the feelings
I have for you ... I love you.

Nevel Humm

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ANNE O'MALLEY

Communicating Together was established in 1982 and has been published quarterly since 1991 by *Sharing to Learn*. Beginning in 1997, it is available both in hard copy and as **ComTog-Online**. The magazine's mandate is to provide a means of sharing the life experiences and communication accomplishments and challenges of augmentative communicators. Its readership includes augmentative communicators, friends, assistants and supporters and all members of the community who wish to know more about those who use augmentative and alternative communication (AAC).

Co-editors:

Peter Lindsay & Shirley McNaughton

Associate Editors: Suzanne Clancy,
Robert Haaf, Paul Marshall, Nola Millin,
Tracy Shepherd, Alda Steprans, Geb Verburg.

Editorial aid: Barbara Reid

Administrative Assistance: Bob McNaughton

Subscriptions: Ruth Kennedy

Desk Top Publishing: Peter Lindsay

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Direct correspondence regarding

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Communicating Together

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Barbara Collier enjoying some fun with Laura Lesker, Aaron Shelbourne, and Tony Diamanti, at *Communicating with Your Attendants Workshop*.

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Phone enquiries: 519-766-1757

Fax: 519-763-6682

Email: plindsay@oise.utoronto.ca
smcnaughton@freespace.net